An Exploratory Analysis of the Potential Association Between SCI Secondary Health Conditions and Daily Activities

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Background: Secondary health conditions (SHCs) are common following traumatic spinal cord injury (tSCI) and are believed to influence a person's ability to participate in daily activities (DAs). This association should be understood so that health care providers may target interventions with clarity and purpose to manage SHCs and facilitate DAs to maximal effect. **Objective**: To explore the association between SHCs and DAs expressed as the increased chance of not participating as much as wanted in a DA when an SHC is present. **Methods**: Community-dwelling persons with tSCI (n = 1,137) responded to the SCI Community Survey. The occurrence and frequency of 21 SHCs were determined. The extent of participation in 26 DAs was measured. The relative risk (RR) of not participating as much as wanted in a DA when a SHC is present was calculated. **Results**: When some SHC were present, the RR of not participating as much as wanted increased significantly (range, 15%-153%; $P < .001$). Certain SHCs (light-headedness/dizziness, fatigue, weight problems, constipation, shoulder problems) were associated with a greater chance of not participating in many DAs. No single SHC was associated with every DA and conversely not every DA was associated with an SHC. **Conclusions**: Maximizing participation in DAs requires minimizing SHCs in every instance. Understanding the association between SHCs and DAs may facilitate targeted care resulting in less severe SHCs, greater participation in DAs, and benefits to both the individual and society. **Key words**: *activities of daily living, participation, secondary health conditions, social integration, traumatic spinal cord injury*

People with traumatic spinal cord injury (tSCI) live with substantial changes in body structures (cardiovascular and respiratory systems, musculoskeletal, skin, etc) and functions (genitourinary, pain, etc).[1] Depending on the location and severity of the spinal cord lesion, these permanent changes significantly impact an individual's ability to participate in a host of meaningful daily activities (DAs) including mobility, self-care, domestic life, relationships, and social and civic life that, as a whole, underpin social integration through participation.[1]

In addition, these individuals experience a variety of secondary health conditions (SHCs) commonly associated with tSCI (fatigue, neurologic deterioration, respiratory infections, etc), which appear to be the main reason for family physician contacts in more than 50% of people with SCI.[2] This high prevalence of SHCs has been reported for decades[3-7] in several studies worldwide, including reports in Canada, and is a significant concern.[8-10] Moreover, quality of life is affected by SHCs,[8,11] their prevalence tends to increase over time,[9] and they place people with SCI at a higher risk of mortality.[12]

One can hypothesize that this high prevalence of SHCs may further intensify the difficulty individuals already experience when attempting to reach the ultimate goal of rehabilitation (coming back to a life worth living[13]) and later when attempting to participate as much as wanted in particular life situations in the community setting. Not surprisingly, as many as one-quarter of the people living with SCI report limitations in social activities secondary

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to poor health, not feeling well, and complications related to pain, incontinence, aging, poor bladder and bowel management, and fatigue.[14] Therefore, maximizing good health and participation in life situations through satisfactory management of SHCs is necessary from both an individual human rights and a social health economic perspective. Despite this, even though various reports suggest that the presence of psychological complications and the number of medical complications are associated with social functioning or integration[15,16] and that people aging with SCI seem to be vulnerable to SHCs, which increases the probability of requiring additional help for their DAs,[17] the extent to which SHCs interfere with the performance of DAs and, ultimately, community participation is not clear.

The purpose of this article is to describe the association between post-tSCI SHCs and the ability of people to participate in DAs (mobility, self-care, domestic life, relationships, and social and civic life) by determining the increased risk of not participating as much as wanted in DAs when an SHC is present. By examining this dynamic, health care providers can gain a deeper understanding of the interplay between SHCs and DAs that may facilitate their ability to target care with greater clarity and purpose. By minimizing the negative effects of SHCs and maximizing participation, benefits to both the individual and society can be achieved.

Methods

Participants/Setting

The SCI Community Survey (SCICS) was created to portray the life situation of people with SCI living in the community setting (including occurrence of SHCs, degree of participation in major life areas including productive activities, and quality of life) and their needs (met or unmet) for services. Major dimensions of living with SCI, including the presence of SHCs and the ability to participate in DAs, were investigated. Eligibility to participate in the survey included living in the community (ie, discharged from a hospital or rehabilitation setting) a minimum of 1 year, a minimum of 18 years old, able to speak and read French or English, and able to provide consent to participate. An in-depth description of the methodology is provided in the first article of this issue.[18] The current study includes only participants with a traumatic mechanism of injury. Ethical approval for this study was obtained from the Canadian Institutional Review Board Services and the Comité d'éthique de la recherche de l'Université Laval.

Instruments used

Two instruments, the SCI Health Questionnaire: Secondary Complications (SCI-HQ) and the person-perceived Participation in Daily Activities Questionnaire (PDAQ), that were originally created for the Rick Hansen SCI Registry Community Follow-Up Questionnaire V2.0[19] were included in the survey. Both instruments were developed using the World Health Organization's International Classification of Functioning, Disability and Health framework.[1] The testing of reliability and validity is reported elsewhere.[19]

The SCI-HQ, based on 21 typical SHCs most commonly reported in the SCI literature (**Appendix A**), requires participants to describe the SHCs they experienced in the last 12 months. For the purpose of this study, only data describing occurrence and frequency (measured on a 6-point scale ranging from *never* to *every day*) was used.

The PDAQ, based on 26 key DAs (**Appendix B**), requires participants to describe their participation in DAs in the last 12 months. For the purpose of this study, only data describing the extent of participation (measured on a 4-point scale from *yes - as much as I want* to *no - and I don't want to do it*) was used. Full methodological information can be viewed at cirris.ca/tscir.html

Analysis

All 21 SHCs and all 26 DAs were included in the analysis. Data were integrated to investigate the association between SHCs and DAs and relative risks (RRs), the ratio of the probability of not participating as much as wanted in a DA when an SHC is present as compared to the probability of not participating when the SHC is not present, were assigned. Determination of the significance of a RR for the total sample (n = 1,137) used a strong criterion (α = 0.001), because the large sample size increased statistical power. Without this severe criterion, several weak RRs would have

been highlighted, possibly shadowing the significance of those that are more clinically meaningful. When analyses were based on SCI severity, a less severe criterion ($\alpha = 0.01$) was used. Statistical analysis was performed using IBM SPSS version 21.0 (IBM Corp., Armonk, NY) and the R software version 2.14. Crosstabs were used to demonstrate the interrelations between variables. To ensure that only participants with tSCI were included in the analysis based on neurologic grouping, we checked and validated the (self-reported) classifications. In all cases of ambiguous response, participants were excluded from the secondary analysis.

Results

Participants

There were 1,137 individuals with tSCI who completed the survey (age, 48.3 ± 13.3 years; time since injury, 18.4 ± 16.3 years). The sample included participants living either in large cities or small communities representing most Canadian regions. Ninety percent of the participants are Caucasian, 40% live with a spouse, an additional 10% live with a spouse and children. Comprehensive demographic and injury information is extensively described in the first article in this issue.[18]

Prevalence of SHCs

The SCICS findings indicate a high prevalence of SHCs,[18] as they were reported by more than 40% of the participants in 50% of the 21 SHCs. Neuropathic pain, sexual dysfunction, and spasticity were the most prevalent, affecting more than 60% of the participants. Additionally, 99% (n = 1,125) of all participants (with SCI of any origin) experienced at least 1 SHC in the 12 months preceding survey completion; 25.7% experienced 1 to 5, 21% experienced 6 to 7, and 52.3% experienced 8 or more (mean value, 8 ± 3.7).

Extent of participation

The extent of participating as much as wanted significantly varied between the 26 PDAQ items across the entire cohort (N = 1,137). Although the majority of participants (60%-85%) reported that they performed some activities as much as wanted (eg, communicating with others, feeding oneself, grooming, performing bowel and bladder care), specific activities primarily associated with social roles (eg, partner relationships, family responsibilities, recreation and leisure, productive activities) were carried out as much as wanted by less than 40% of the participants.[18]

Association between DAs and SHCs

In the context of performing DAs as much as wanted, the presence of an SHC increased the probability of not participating in every instance. When considering all potential associations between the 21 SHCs and 26 DAs (n = 546) leading to a calculation of RR, 39% were statistically significant ($P \leq .001$). **Table 1** shows the increased RR of not participating in a DA in the presence of different SHCs for all tSCI participants. Certain SHCs were associated with many DAs, including light-headedness/dizziness (all 26 DAs), fatigue (n = 21), neurologic deterioration (n = 21), and respiratory infections (n = 18). In contrast, others were associated with few or none: elbow/wrist problems (n = 5), pressure ulcers (n = 4), autonomic dysreflexia (n = 4), thrombosis/embolism, and urinary incontinence (n = 0). Overall, the RR values ranged from 1.15 to 2.53; this was a 15% to 153% increased probability of not participating as much as wanted in a particular DA, when a specific SHC is present.

The RR analyses based on SCI severity groupings revealed many significant associations and a large variation in the increased risk of not participating in a DA in the presence of different SHCs. Respectively, 8.4%, 22.5%, and 24.9% of potential SHC-to-DA associations were statistically significant in the tetraplegia American Spinal Injury Association Impairment Scale (AIS) ABC, all AIS D, and paraplegia groups. More specifically, **Table 2** shows the 4 SHCs with the most associations for each severity group. The tetraplegia AIS ABC group showed 25 associations out of a possible 104 (RR range, 1.19-2.46); AIS D showed 55 associations (RR range, 1.40-4.70), and paraplegia AIS ABC showed 71 associations (RR range, 1.32-4.16), suggesting that this group could be at greatest risk of not participating in the presence of SHCs. Further, the following SHCs were associated with the greatest number of DAs and increased the RR of not participating: shoulder problems (n = 9) and

Table 1. Relative risks[a] of not participating in activities in the presence of different secondary health complications (SHCs) for all participants having a traumatic lesion

Activities	*n*[b]	Light headedness/ dizziness	Fatigue	Neurological deterioration	Respiratory infections	Constipation	Injuries due to loss of sensation
Performing bladder care	1,091	2.39			1.63		
Feeding yourself	1,131	2.38			2.24		
Grooming	1,124	2.33	1.55	1.56	1.98		
Communicating by electronic means	1,117	2.07	1.78	2.53	2.39	2.04	1.96
Communicating with others	1,126	2.00	2.44	2.02	1.70	1.83	1.94
Moving using transportation	1,108	1.99	1.64	1.74		1.42	1.43
Washing	1,120	1.92	1.36	1.44	1.59		
Dressing	1,099	1.90			1.66		
Preparing meals	1,050	1.85	1.38		1.46		
Carrying-out civic responsibilities	1,007	1.80	1.60	1.58	1.50		1.44
Performing bowel care	1,082	1.79		1.39	1.46	1.41	
Carrying-out financial responsibilities	1,094	1.76		1.68		1.72	
Accessing services in your community	1,121	1.70	1.43	1.35	1.36	1.35	1.38
Maintaining relationships with others	1,136	1.67	1.98	1.37	1.56		1.59
Maintaining mental well-being	1,078	1.60	1.78	1.61	1.44	1.55	1.65
Participating in activities and organizations	725	1.58	1.67	1.56			1.38
Preparation to paid job	657	1.54	1.44	1.30		1.33	
Moving within home	1,132	1.54	1.60	1.73	1.53	1.39	1.33
Carrying-out paid productive activities	762	1.51	1.33	1.34			1.27
Leisure and recreational activities	995	1.40	1.46	1.33			1.26
Maintaining/forming a partner relation	1,021	1.34	1.44	1.25	1.33		1.38
Carrying-out family responsibilities	969	1.33	1.32			1.32	
Carrying-out unpaid productive activity	895	1.33	1.44	1.31		1.29	1.31
Participating in holiday and traveling	1,040	1.31	1.19	1.17	1.20	1.24	
Maintaining physical health	1,091	1.30	1.23	1.20	1.29	1.20	1.19
Carrying-out activities related to home	1,034	1.28	1.27	1.18	1.30	1.22	

Note: Data are listed in a decreasing order of relative risk (RR) for the SHC with the most RR. Only statistically significant RRs are presented ($P \leq .001$).

[a]The RR is the probability of an event occurring (not participating in a societal activity as much as wanted) in a group with a specific characteristic (having an SHC) divided by the probability of the same event occurring in a group with another characteristic (**not** having an SHC).

[b]Sample size varies between activities because people who did not want to participate in a specific activity were not included in the analysis.

light headedness/dizziness ($n = 7$) in tetraplegia AIS ABC, constipation ($n = 21$) and fatigue ($n = 20$) in paraplegia AIS ABC, and fatigue ($n = 18$) and weight problems ($n = 14$) in AIS D.

Discussion

The purpose of this article is to explore potential associations between SHCs and DAs represented as the ratio of the probability of not participating as much as wanted in a DA when an SHC is present. To our knowledge, this study is the first to describe how 21 typical SHCs and participation in 26 key DAs are associated in the context of achieving maximal social integration through participation in various domains (eg, mobility, self-care, domestic life, relationships, and social and civic life). The survey approach did not propose a quantitative measure of participation, instead participants were able to consider their participation individually on the basis of their perceptions and preferences. Accordingly, we assume that participants rated

Table 1. Continued

Trouble sleeping	Shoulder problems	Weight problems	Joint contractures	Neuropathic pain	Urinary tract infection	Spasticity	Bowel incontinence	Sexual dysfunction	Elbow/ wrist problems	Pressure ulcers	Autonomic dysreflexia
				~	1.78	1.71					1.55
	1.79					1.85					
	1.63				1.55	1.53				1.52	1.66
				2.41							
	1.68		1.74	2.09				1.76			
1.57	1.44	1.41	1.39	1.56					1.47		
	1.36	1.49			1.46	1.46				1.41	
					1.51						
	1.36				1.46	1.52					1.37
1.45	1.43						1.44				
	1.42				1.54	1.66	1.35				1.51
	1.36		1.32				1.36	1.42	1.32		
1.57		1.41		1.61			1.44	1.55			
1.46		1.36									
1.40	1.43	1.61									
1.42	1.37	1.32	1.33	1.47		1.31	1.32		1.30		
1.40			1.39						1.34		
1.36			1.26	1.31			1.25				
1.37	1.21	1.31	1.31	1.33							
1.29		1.38		1.30				1.42		1.33	
								1.35			
1.40											
1.23		1.15	1.19	1.17	1.19			1.17	1.18		
1.24		1.27			1.27						
		1.18	1.18		1.24		1.24			1.18	

participating "as much as wanted" based on their view of their optimal involvement in society.

Such an exploration is a first step in determining whether or not SHCs influence participation in DAs. Although an RR significantly greater than 1 is indicative of a greater chance of not participating as much as wanted when an SHC occurs, it is important to remember that the RR describes an association and not causality. Also, when interpreting an RR, the nature and the baseline frequency of the activity must be kept in mind. For instance, an RR of 2.0 means a 100% increased risk of not participating. Because RR is a ratio, 2.0 may be 2% of nonparticipation for those who experience an SHC compared to 1% of nonparticipation for those without this SHC. It may also be 30% compared to 15%. Consequently, a 100% increase of nonparticipation for a rare behavior may not be as dramatic as a 100% increase for a frequent behavior. However, if the consequence of nonparticipation in a DA is detrimental, even though it is rare, an RR of 1.1 (10% increase) is far more

Table 2. Relative risks[a] of not participating in activities in the presence of different secondary health complication for the 3 different lesion groups having a traumatic lesion

	Tetraplegia and paraplegia, AIS D (n = 171; range, 95-171) [b]			
Activities	**Fatigue**	**Weight problems**	**Constipation**	**Trouble sleeping**
Communicating with others	3.61		2.90	
Participating in activities and organizations	3.32			
Moving using transportation	2.51	2.20	2.20	2.59
Preparation to paid job	2.47	2.14	2.81	2.04
Maintaining relationships with others	2.33	2.59	1.78	1.70
Washing	2.32	2.31		
Preparing meals	2.21		2.13	
Carrying-out financial responsibilities	2.19			
Maintaining mental well-being	2.03	1.82	2.01	1.77
Accessing services in your community	1.96	2.49	2.12	1.90
Carrying-out family responsibilities	1.85			1.61
Participating in holiday and traveling	1.78	1.54	1.79	1.79
Maintaining/forming a partner relationship	1.76	2.23	1.81	
Moving within home	1.68			1.69
Carrying-out unpaid productive activities	1.58	1.51	1.58	1.56
Carrying-out productive activities paid for	1.51			
Carrying-out activities related to your home	1.49	1.40	1.57	
Leisure and recreational activities	1.45			
Communicating by electronic means		2.71	4.70	
Dressing		2.49		
Maintaining physical health		1.52	1.45	1.55
Performing bowel care		2.30		
Feeding yourself				
Performing bladder care				
Carrying-out civic responsibilities				
Grooming				

Note: Data are listed in a decreasing order of relative risk (RR) for the secondary health complication (SHC) with the most RR. Only statistically significant RRs are presented ($P \leq .01$). AIS = American Spinal Injury Association Impairment Scale.

[a]The RR is the probability of an event occurring (not participating in a societal activity as much as wanted) in a group with a specific characteristic (having an SHC) divided by the probability of the same event occurring in a group with another characteristic (**not** having an SHC).

[b]Sample size varies between activities because people who did not want to participate in a specific activity were not included in the analysis.

important than an RR of 1.5 (50% increase) for the nonparticipation in a less vital activity. The absolute value of an RR must be balanced with the nature and frequency of both DA and SHC.

The main findings of this study support the hypothesis that SHCs interfere with achieving a satisfactory level of participation in a variety of DAs. Further, this potential interference from SHCs seems to differ according to the type and severity of lesion. The paraplegia AIS ABC group appears to be most impacted as suggested by the large number of SHC-to-DA associations. It may be that this group possesses enough physical ability to participate in many DAs but has sustained enough severity of injury to render them susceptible to the effects of SHCs. It is commonly believed that although modifications to routines and use of equipment will be required, people with paraplegia

Table 2. Continued

Paraplegia, AIS ABC (n = 468; range, 274-467)[b]				Tetraplegia, AIS ABC (n = 368; range, 220-367)[b]			
Constipation	Fatigue	Neurological deterioration	Light headedness/ dizziness	Shoulder problems	Light headedness/ dizziness	Injuries due to loss of sensation	Pressure ulcers
2.35	2.94	2.56		1.98		2.03	
1.93	1.94	1.76	1.87	1.58			
	1.75	1.93	2.36	1.55	1.65		1.58
1.71	1.46		1.85	1.50		1.43	
	2.37			1.54	1.69		
	1.88	2.16	2.07		1.45		1.34
1.93	1.90	1.82	1.87				
2.78	1.84	2.39					
1.65	2.07		2.17			1.64	
	1.82	1.50	1.92	1.42			
1.42			1.56				
1.40					1.19		
	1.38	1.37					1.37
1.81	2.05	1.90	1.85				
1.45	1.45		1.51	1.40			
1.46			1.71		1.34	1.37	
1.42	1.32	1.37					
1.39	1.52	1.35	1.56	1.42	1.41	1.31	
2.90		2.90					2.46
2.25	1.90	1.87					
1.26							
3.42	2.74	2.70					
4.21		4.16		1.72			
3.45	2.50	2.54			1.42		
1.89	1.74		2.11				
3.24	2.85	3.17					

(mostly because they retain full upper extremity function) can be fully independent with DAs and can participate as much as wanted in many of them. In some respects, this is an oversimplification of the complexities of living with SCI, yet it is reasonable to imagine that these individuals have high expectations and desire to participate. Consequently, the occurrence, frequency, and severity of SHCs that get in the way of participating in life situations might definitely limit the ability to participate as much as wanted. For instance, managing constipation (the "top" SHC) as part of bowel care can be time consuming and disruptive to daily schedules and can be associated with episodes of bowel incontinence once treatments take effect. Given the social stigma related to incontinence, one may imagine it as an actual limitation in participation as much as wanted. Fatigue is also a

recognized problem in the SCI literature, and its effects can be easily understood as a limitation to participation in any/all DAs.

Individuals with tetraplegia or paraplegia AIS D generally possess more physical ability, bear less severity of injury, and show fewer instances of participation interference likely because they are less hindered overall. Despite this, the number of associations between SHCs and DAs still remains relatively high, suggesting that this group feels the effect of the occurrence of SHCs as indicated by the significant associations between most DAs and fatigue, weight problems, constipation, and trouble sleeping. It also strongly suggests a clear need for medical or functional evaluations despite, in many cases, the fact that this group appears to be the most "well" as compared to their SCI counterparts.

Finally, persons with tetraplegia AIS ABC carry the highest severity of injury and are known to experience a high incidence of SHCs. However, even though the presence of an SHC still increases their chance of not participating as much as wanted in a DA, this interplay occurs less. In contrast to the first 2 groups, these individuals possess the least physical ability. It may be that their desire to participate remains high, but a (forced) tempering of expectations about participation exists and a shift in their view of their optimal involvement in society has occurred. Accordingly, the nature of their participation is likely very different from the other groups and their approach to rating their participation (based on a different set of expectations about participation) may differ. Additionally, such individuals typically receive higher levels of care and support (either at home or in facility) where SHCs may be better managed, generally, and the influences of SHCs may not be as limiting. Future work could be undertaken to determine the validity of these particular hypotheses. Nevertheless, there still exists a moral and practical imperative to minimize the impact of SHCs and maximize an individual's ability to participate in DAs with the aim to improve social integration for all people with SCI.

Several reports indicate that SHCs typically associated with SCI are prevalent and problematic; they are well understood and thoroughly documented as problems post SCI.[3-10,20] In an overloaded health care system where it is common to have to make exacting decisions, health care providers must target their interventions with clarity and purpose. By developing an awareness of the SHCs typically experienced by individuals with tSCI and the DAs that are necessary for social integration – and by understanding the associations between them – health care providers can use this knowledge to make decisions about what to do first and how to make the most out of every intervention; they can expand their interventions by including new actions not previously considered. Beyond the obvious benefits of improved health, managing SHCs by considering their association with the performance of DAs has the additional incentive of enhancing societal integration, particularly in view of the consequences to the individual and society when health and participation are not maximized.

Impact on policy

Parties to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) are required to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.[21] CRPD articles outline the enjoyment of the highest attainable standard of health (Article 25) and participation on an equal basis with others (Articles 29, 30).

In a commentary outlining existing research to highlight the complexities of SHCs and their impact on perceptions of QOL, Hammell reported that researchers should focus on issues and outcomes of relevance and importance to people living with SCI, address the complexities of secondary conditions and their interrelationships, appraise environmental barriers to participation in meaningful living, and ensure that future research endeavors are designed to identify and inform effective and relevant interventions.[11]

People with disabilities have specifically asked to be more involved in their own care and for researchers to enhance the usefulness and relevance of their work by collaborating more with them.[22] This is supported by the CRPD, which rec-

ognizes the importance of their individual autonomy and independence, including the freedom to make their own choices, and considers that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them.[21]

Limitations

There are several limitations in this survey that must be acknowledged. First, the recruitment process did not allow the selection of participants through a randomized process and the level of participation is uneven across Canada, creating a potential selection bias and a nonresponse bias. Although the geographical distribution of participants approaches the distribution of the adult population within Canada, it was not possible to calculate a representational weight for each observation. Second, the study is based on self-reported data that cannot be validated by external data, and the high number of sections and questions may have induced fatigue or boredom in participants leading to under- or overestimation of behaviors, beliefs, and knowledge and consequently to a potential information bias. Associated with such a bias is the 12-month retrospective time period used to determine the occurrence of SHCs that might have been unequally estimated by participants compared to a more recent situation. Third, several questions offered predefined ordinal or Likert-scale answer options and participants might have been constrained by these predefined categories, leading to potential central tendency (avoiding the use of extreme response categories) or acquiescence (agreement with a statement when in doubt) biases. Fourth, the period to complete the survey lasted more than a week or a month for 25% and 15% of participants, respectively, which might have created a form of recall bias. Fifth, the estimation of the severity of injury relied on self-report information of motor and sensory recovery and is not as accurate as an actual medical assessment leading to a potential misclassification of the AIS grade.

Conclusions

SHCs are common in the tSCI population, and the survey findings suggest they are associated with an increased chance of not participating as much as wanted in a DA when present. This interplay can result in greater risk to the individual (decreased involvement in a wide variety of life situations) and society (increased burden of care including provision of extra daily physical assistance and health services, as well as loss of economic potential).

SHCs must be identified and resolved to the greatest extent possible so that participation in life situations (at the individual level) or engagement in full community participation (at the societal level) is not hindered. To achieve meaningful and efficacious outcomes, a comprehensive assessment by the health care provider should emphasize both health status and impact on daily living and should include the perspectives of the person with SCI. In addition, people living with tSCI must be given the opportunity for meaningful collaboration in future research endeavors.

By understanding the association between specific SHCs and particular DAs, health care providers, with greater clarity and purpose, may enhance their interventions by including actions not previously considered that are aimed at eliminating this situation.

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APPENDIX A

SCI Health Questionnaire: Secondary Complications

1) In the past 12 months, have you experienced this problem? (Choose ONE)						
Never	Don't know	Once a year	A few times a year	A few times a month	A few times a week	Every day
Skip to the next secondary complication		**2) You mentioned that you experienced _____ in the past 12 months.** **Did you seek, or are you receiving some form of treatment for this problem?**				
		Yes or No				
3) When you had this problem, to what extent did it limit your activities? (Choose ONE)						
Not at all	Very little	To some extent	To a great extent	Completely		

Secondary Health Complication Items

1.	Neuropathic pain	2.	Sexual dysfunction
3.	Joint contractures	4.	Spasticity
5.	Urinary tract infection	6.	Shoulder problems
7.	Bowel incontinence	8.	Weight problems
9.	Urinary incontinence	10.	Trouble sleeping
11.	Elbow/wrist problems	12.	Neurological deterioration
13.	Fatigue	14.	Pressure ulcers
15.	Constipation	16.	Injuries caused by a loss of sensation
17.	Light headedness/dizziness	18.	Respiratory infections
19.	Autonomic dysreflexia	20.	Thrombosis/embolism
21.	Kidney/bladder stones		

APPENDIX B

Participation in Daily Activities Questionnaire

Questions:		Answers:
1.	**Do you participate in this activity?** (CHECK ONE)	☐ 1. Yes – as much as I want.
		☐ 2. Yes – but less than I want.
		☐ 3. No – but I would like to do it.
		☐ 4. No – and I don't want to do it. →**SKIP TO NEXT ACTIVITY**

Questionaire items

1. Communicating with others by electronic means	2. Communicating with others
3. Feeding yourself	4. Grooming
5. Carrying-out financial responsibilities	6. Performing bladder care
7. Moving from one place to another using transportation	8. Maintaining relationships with others
9. Maintaining your mental well-being	10. Dressing and undressing
11. Performing bowel care	12. Washing
13. Moving from one place to another in nearby surrounding	14. Carrying-out civic responsibilities
15. Accessing services in your community	16. Preparing meals
17. Carrying-out family responsibilities	18. Maintaining or forming a new spouse/partner relationship
19. Carrying-out productive activities that are unpaid	20. Participating in activities and organisations
21. Maintaining your physical health	22. Participating in leisure and recreational activities
23. Carrying-out activities related to your home	24. Carrying-out productive activities that you are paid for
25. Participating in holiday and traveling activities	26. Activities that prepare you to start working in a paid job